

ICC Conference Call
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Successful Strategies & Materials for Outreach to Hispanic Families

Present:

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Introductions

Zoila-from Mexico, has 2 children, her daughter has Down Syndrome & is 6 years of age

Graciela-from Peru & has a 5 yr.old son with Down Syndrome

Nina-has 2 grandchildren 15 y.o & 4 y.o both were in EI

Marilyn:

- The topic for today's call is successful strategies for outreach for Hispanic families
- Good opportunity to hear from other states and to learn what strategies they use and services they offer

Maria:

Our main strategy is translation, but that is pretty typical, so I do not need to go into that

Nina:

It would be great if you could go into greater detail as we are looking for more information on translation

Maria:

- We have a core group of families that are involved in EI or have been out of EI for just a few years
- We have these parents read our translations to see if they are meaningful
- There is a mother originally from Mexico who does great translations and brings it down to an appropriate reading level
- Translates all materials & newsletters
- Serve 2 counties and 1 Native American reservation the size of CT with many Spanish speaking families
- Try to have enough bi-lingual staff to serve these families
- Meet with various groups to get our names out into the community such as the Down Syndrome Connection which is made up of Spanish speaking families only

Zoila:

Is the Down Syndrome Connection only for Hispanic families?

Maria:

For several groups, but there is one monolingual group led by a Hispanic woman

Zoila:

I would love to get her contact info

Zoila & Maria exchanged contact info

Graciela:

Also like more info on Down Syndrome group for Hispanic Families

Nina:

- We try to reach families in a number of ways
- Have had pretty good luck in the Lexington community because of a lady who is always willing to translate whenever we come out
- Organize meetings for families to meet and network
Sunday afternoon after church is the best time...families are all together
30-40 parents with children...important to Hispanic families that they attend with their whole families
This is part of their culture and we accommodate as best we can, even if it means talking over crying children
- In Omaha, outreach through local ICC, Planning Region Teams-get info to families & ask them what they need
- Contact with Spanish speaking families...meet, give information to families & hear their needs, try to organize and schedule meetings
- Wanted to participate on this call because we are having small successes, which can turn into big successes, but no continuous results
- We have just hired Graciela and Joan so that our success will become more continuous

Graciela & Joan:

- Meeting with different Hispanic organization members
- Outreach through different groups...a lot of Hispanic leaders
- Letting know about PTI and giving them translated materials
- Invited leaders to an open house – important to know who we are and what we offer so that they can spread the word
- Graciela will give a presentation on IEPs in September with a woman from Lexington
- As time goes by Graciela hopes to give these presentations herself
- Goal = all presentations translated and given in Spanish
- So much info for parents to absorb, and the best way to get this info is in native language
- Important to have native speaker read over translations to make sure that they make sense before they are distributed...have families read materials and then tell us what they liked and disliked about the info

Joan:

- Only second week working on PTI
- Background knowledge on IEPs and parents' rights

Maria:

- Nina mentioned how important it is to include the children in the meetings
- They always try and provide childcare
- Being Hispanic herself, she knows how long it took for her to trust anyone with her grandson!
- Mentioned only small successes, but need to remember that these individual successes can change a life
- Have to keep reminding ourselves!
- Sometimes it is discouraging when you walk into a meeting and there are only 1 or 2 families there, but it is okay!
- One family connecting with another family is so invaluable
- We send out questionnaires to the families once a year, we ask them what made sense & what didn't

Nina:

That's why we keep going for the little successes!

Maria:

- Build core groups of families
- Send out surveys...would you like to read material in the privacy of your own home? What makes sense?
- One parent put a resource book together all from working at home
- Important to let families know about the different opportunities there are to get involved
- Provide many ways to get involved
- Good return rate of surveys
- Families want to know that they can participate!

Joan:

- Has lots of ideas - see where her new ideas will fit in with what is already in existence.
- Graciela and Joan will spend time deciding who is covering what area and what they need to look at more
- They will outreach to minority groups

Graciela:

Lots of Hispanic families in Nebraska, but also a lot of Native American, African American, Sudanese (large population)& Asian families as well

Maria:

- Attended a conference in Phoenix, and the keynote was on multiculturalism and that sometimes we forget that there are commonalities within all families
- Respect and appreciation...all those things that we want from everyone we encounter
- People aren't that different
- Everyone's basic needs are the same
- Make sure the understanding of commonalities are in place, then focus on unique aspects
- Families want respect from everyone, we all do
- Let families know about different opportunities, the many ways they can be involved, let them participate in whatever works for them

Nina:

What I hear you saying is that some times we work too hard on what's different and don't focus on what's the same

Zoila & Susie (Social Worker):

- Began Down Syndrome Association of Atlanta with 8 test groups for a month
- Now 140 families, not exclusively families of children with down syndrome, but 95% of the children have Down Syndrome
- They coordinate the meetings, multi-meetings for everyone in the family
- Children are included, in the back of the same meeting room with someone to care for them while the parents are meeting
- Meetings are held in a Hispanic community so parents can feel comfortable
- Transportation is a big issue for some families, so they provide transportation
- Zoila & the Social Worker she works with have identified with 3 major hospitals where Hispanic women have their babies
- Zoila makes contact with these hospitals and ask that they please tell families about her group when they are ready to talk
- They do homevisits-Zoila takes one part of the community, Susie takes the other part
- Once referred by the hospital, they call the families and provide simple and clear info in Spanish about Down syndrome, health care, etc.
- When the hospital social workers will be out on vacation, Zoila is notified & another Social Worker will call Zoila to let her know she is available-so the word gets out in the hospital
- 99% of the moms experience feelings of guilt, not listening to all of this info about services available

- At the beginning, they work with moms and dads to explain that it is not their fault
- Have a great relationship with one of the local university's Genetics Department...also explain to parents
- Once parents' feelings of guilt have lessened, then they talk about services available
- Have a database with all the professionals who speak Spanish
- Try to promote connections with other families...feel better when they find more Hispanic families in their same situation
- Don't usually use a lot of other interpreters...Zoila & the social worker are both bilingual
- The parents are connected to Hispanic doctors & specialists
- They also promote inclusion with the American community by having conferences, & holiday parties
- Always looking for Spanish speaking presenters...they are lucky they have met a lot of different professionals who speak Spanish

(Please see Zoila's email forwarded to you from Marilyn for more detail)

Maria:

- Zoila, had mentioned the importance of hospitals knowing about the group...Maria has that problem in Arizona as well
- Through hospitals is one of the most powerful ways to reach families
- So heartbroken that their baby looks a little different, they can't even think about services yet
- Take advantage of social workers at hospitals
- Also take advantage of the availability of speakers who do not ask for payment...part of their outreach efforts

Zoila:

- Hospitals are the most important piece
- At first, it is very hard to meet with doctors at the hospital because they are so busy...they have told her to meet them between 4-4:15
- She sent flyers as well saying to give her a call when there is a newborn
- Once the doctors see the impact of our job, they are more open and more willing to give their time
- She has established a very friendly relationship with the hospitals
- In terms of parent involvement with outreach to the hospitals, most of the families don't speak English and don't drive
- Zoila & Susie divide the hospitals between the two of them...it is a lot of work
- The wish they could have more moms willing to help them who can drive and speak English

Nina:

Asked Zoila if she needs to check back with the hospital once she got in touch with them?

Zoila:

- We have not needed to check back with the hospitals...there have been no problems
- During a time when a social worker that she works closely with was on vacation, Zoila got a call from her colleague saying that she was instructed to call Zoila if anything came up

Nina:

Have had trouble in the past...hospitals forget about the info we've given them
Or, our contact will move to a new position, and now all of the info is lost

Zoila:

- It is helpful to find out who is the right person to talk to
- At least send some mailings...they have established regular mailings

Nina:

legal status of families...some are afraid to get services because of their immigration status

Zoila:

- 100% of the families Zoila works with are illegal
- We always tell our families that their child is American
- He or she was born here and has a right to services
- Give support to families to ensure that nothing will happen
- Law is clear...any child 0-3
- Feel in control with EI because they know it is safe
- Service coordinators will help with Medicaid and SSI
- Parents will not call the SSI office, they are afraid of their legal status in the U.S.
- At this moment, it is a major problem
- Immigration officials drive around neighborhoods asking for drivers licenses...people are scared
- Keep telling them that nothing will happen...the services are for their child

Nina:

- Same here...we don't ask the legal questions
- Services are for the child

Zoila:

I always make sure to tell my background...makes families feel closer to me

Is it more important to match the family by disability or by culture?

Zoila:

Disability

Nina:

- I don't think that it matters
- Just having a child with a disability is common ground enough
- A mom of a child with CP and a mom of a child with down syndrome will instantly connect
- Not necessarily the same disability, but any disability
- Down syndrome is no problem to match, but rarer disorders are hard to match, especially when it is a Spanish speaking family

Zoila:

- I've heard parents that don't want to go back, saying that down syndrome is nothing compared to a child with a more severe disability
- Harder for them

Nina:

Some success though when we meld a group together with all disabilities...there is usually at least one other family to connect with

Zoila:

What matters most is understanding that they can cry together

Maria:

- Importance of social workers
- Easy to lose a connection with a hospital
- Make sure that they have the info to share
- Can talk about the materials available, but don't forget the family involvement piece

- Utilize child protection/advocacy groups
- We are introducing a family to so much in such a short period of time
- We need to be knowledgeable on who can speak for free
- I am a big one on accountability...there are groups that receive funds for outreach...use them!
- I had never heard of a support group

Zoila:

Some parents do not know what a support group is...ask if it would help them get their license/green card

Maria:

Talk about parent involvement

We are a link utilizing other agencies

Zoila:

In the Hispanic community, EI, Parent to Parent etc. are all new to these families

They don't know about these agencies & when these agencies call the families they get overwhelmed

Maria:

- Always say that every feeling you have is okay
- We all have these feelings
- I am here as a friend
- To know that you are not alone is all you need to make it through today
- A national conferences, you can go and connect with families from all over the country
- So powerful just for families to get together
- Fall Festival Day/Spring Day in the Park...60 to 80 families attend...time to meet us, other families and have fun
- Exploring many different ways that we can reach families-called churches who target day care centers, families that know other families
- Inform families on services that are available to them
- Outreach through church bulletins as well

Zoila:

- We don't go through churches
- Don't want to be connected to religion
- Keep in mind, not all Spanish speakers are Catholic...don't want to alienate

Maria:

- Important to recognize
- Here, Native American communities have their own beliefs as well
- Difference are many, but commonalities as well

Graciela & Zoila will both be attending the National Down Syndrome Congress in Minneapolis in August

Maria:

Perhaps one day we can do something on a national level

Zoila:

Where do the funds come from?

Maria:

Find out in your state where to tap into funds- PTI centers, EI training centers, Governors council

